

## Calendar No. 369

108TH CONGRESS  
1ST SESSION**S. 286****[Report No. 108–188]**

To revise and extend the Birth Defects Prevention Act of 1998.

## IN THE SENATE OF THE UNITED STATES

FEBRUARY 4, 2003

Mr. BOND (for himself, Mr. DODD, Mr. FRIST, Mr. KENNEDY, Mr. DEWINE, Ms. LANDRIEU, and Mr. SMITH) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

NOVEMBER 6, 2003

Reported by Mr. GREGG, with an amendment

[Strike out all after the enacting clause and insert the part printed in italic]

**A BILL**

To revise and extend the Birth Defects Prevention Act of  
1998.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Birth Defects and De-  
5 velopmental Disabilities Prevention Act of 2003”.

1 **SEC. 2. NATIONAL CENTER ON BIRTH DEFECTS AND DE-**  
 2 **VELOPMENTAL DISABILITIES.**

3 Section 317C of the Public Health Service Act (42  
 4 U.S.C. 247b-4) is amended—

5 (1) in subsection (a)(2)—

6 (A) in subparagraph (A)—

7 (i) by striking “and developmental  
 8 disabilities” and inserting “, developmental  
 9 disabilities, and disabilities and health”;  
 10 and

11 (ii) by striking “subsection (d)(2)”  
 12 and inserting “subsection (c)(2)”;

13 (B) in subparagraph (B), by striking  
 14 “and” at the end;

15 (C) in subparagraph (C), by striking the  
 16 period and inserting a semicolon; and

17 (D) by adding at the end the following:

18 “(D) to conduct research on and to pro-  
 19 mote the prevention of such defects and disabil-  
 20 ities; and secondary health conditions among in-  
 21 dividuals with disabilities; and

22 “(E) to support a National Spina Bifida  
 23 Program to prevent and reduce suffering from  
 24 the Nation’s most common permanently dis-  
 25 abling birth defect.”;

26 (2) by striking subsection (b);

1           (3) in subsection (d)—

2                   (A) by striking paragraph (1) and insert-  
3           ing the following:

4           “(1) contains information regarding the inci-  
5           dence and prevalence of birth defects, developmental  
6           disabilities, and the health status of individuals with  
7           disabilities and the extent to which these conditions  
8           have contributed to the incidence and prevalence of  
9           infant mortality and affected quality of life;”;

10                   (B) in paragraph (3), by inserting “, devel-  
11           opmental disabilities, and secondary health con-  
12           ditions among individuals with disabilities”  
13           after “defects”;

14                   (C) in paragraph (4), by striking “and” at  
15           the end;

16                   (D) by redesignating paragraph (5) as  
17           paragraph (7); and

18                   (E) by inserting after paragraph (4) the  
19           following:

20           “(5) contains information on the incidence and  
21           prevalence of individuals living with birth defects  
22           and disabilities or developmental disabilities, infor-  
23           mation on the health status of individuals with dis-  
24           abilities, information on any health disparities expe-  
25           rienced by such individuals, and recommendations

1 for improving the health and wellness and quality of  
 2 life of such individuals;

3 “(6) contains a summary of recommendations  
 4 from all birth defects research conferences sponsored  
 5 by the Centers for Disease Control and Prevention;  
 6 including conferences related to spina bifida; and”;

7 (4) in subsection (c)—

8 (A) by inserting “, including section 444 of  
 9 the General Education Provisions Act,” after  
 10 “privacy of information”; and

11 (B) by inserting before the period the fol-  
 12 lowing: “, except that the Centers for Disease  
 13 Control and Prevention shall have access to in-  
 14 formation under section 444(b)(1)(F) of such  
 15 Act solely for purposes of carrying out sub-  
 16 section (a)(2) of this section and shall otherwise  
 17 comply with all other requirements of such sec-  
 18 tion 444”;

19 (5) by redesignating subsections (c), (d), and  
 20 (e) as subsections (b), (c), and (d), respectively;

21 (6) by inserting after subsection (d) (as so re-  
 22 designated), the following:

23 “(e) ADVISORY COMMITTEE.—Notwithstanding any  
 24 other provision of law, the members of the advisory com-  
 25 mittee appointed by the Director of the National Center

1 for Environmental Health that have expertise in birth de-  
 2 feets, developmental disabilities, and disabilities and  
 3 health shall be transferred to and shall advise the National  
 4 Center on Birth Defects and Developmental Disabilities  
 5 effective on the date of enactment of the Birth Defects  
 6 and Developmental Disabilities Prevention Act of 2003.”;  
 7 and

8 (7) in subsection (f), by striking “\$30,000,000”  
 9 and all that follows and inserting “such sums as  
 10 may be necessary for each of fiscal years 2003  
 11 through 2007.”.

12 **SEC. 3. TECHNICAL CORRECTIONS FOR STATE COUNCILS**  
 13 **ON DEVELOPMENTAL DISABILITIES.**

14 Section 122(a) of the Developmental Disabilities As-  
 15 sistance and Bill of Rights Act of 2000 (42 U.S.C.  
 16 15022(a)) is amended—

17 (1) in paragraph (3)(A)(ii), by inserting before  
 18 the period the following: “; the amount received by  
 19 the State for the previous year, or the amount of  
 20 Federal appropriations received in fiscal year 2000,  
 21 2001, or 2002, whichever is greater”; and

22 (2) in paragraph (4)(A)(ii), by inserting before  
 23 the period the following: “; the amount received by  
 24 the State for the previous year, or the amount of

1 Federal appropriations received in fiscal year 2000;  
 2 2001, or 2002, whichever is greater”.

3 **SECTION 1. SHORT TITLE.**

4 *This Act may be cited as the “Birth Defects and Devel-*  
 5 *opmental Disabilities Prevention Act of 2003”.*

6 **SEC. 2. NATIONAL CENTER ON BIRTH DEFECTS AND DEVEL-**  
 7 **OPMENTAL DISABILITIES.**

8 *Section 317C of the Public Health Service Act (42*  
 9 *U.S.C. 247b–4) is amended—*

10 *(1) in subsection (a)(2)—*

11 *(A) in subparagraph (A)—*

12 *(i) by striking “and developmental dis-*  
 13 *abilities” and inserting “, developmental*  
 14 *disabilities, and disabilities and health”;*  
 15 *and*

16 *(ii) by striking “subsection (d)(2)” and*  
 17 *inserting “subsection (c)(2)”;*

18 *(B) in subparagraph (B), by striking “and”*  
 19 *at the end;*

20 *(C) in subparagraph (C), by striking the*  
 21 *period and inserting a semicolon; and*

22 *(D) by adding at the end the following:*

23 *“(D) to conduct research on and to promote*  
 24 *the prevention of such defects and disabilities,*

1           *and secondary health conditions among individ-*  
 2           *uals with disabilities; and*

3           *“(E) to support a National Spina Bifida*  
 4           *Program to prevent and reduce suffering from*  
 5           *the Nation’s most common permanently dis-*  
 6           *abling birth defect.”;*

7           *(2) by striking subsection (b);*

8           *(3) in subsection (d)—*

9           *(A) by striking paragraph (1) and inserting*  
 10          *the following:*

11          *“(1) contains information regarding the inci-*  
 12          *dence and prevalence of birth defects, developmental*  
 13          *disabilities, and the health status of individuals with*  
 14          *disabilities and the extent to which these conditions*  
 15          *have contributed to the incidence and prevalence of*  
 16          *infant mortality and affected quality of life;”;*

17          *(B) in paragraph (3), by inserting “, devel-*  
 18          *opmental disabilities, and secondary health con-*  
 19          *ditions among individuals with disabilities”*  
 20          *after “defects”;*

21          *(C) in paragraph (4), by striking “and” at*  
 22          *the end;*

23          *(D) by redesignating paragraph (5) as*  
 24          *paragraph (7); and*

1                   (E) by inserting after paragraph (4) the fol-  
 2                   lowing:

3                   “(5) contains information on the incidence and  
 4                   prevalence of individuals living with birth defects and  
 5                   disabilities or developmental disabilities, information  
 6                   on the health status of individuals with disabilities,  
 7                   information on any health disparities experienced by  
 8                   such individuals, and recommendations for improving  
 9                   the health and wellness and quality of life of such in-  
 10                  dividuals;

11                  “(6) contains a summary of recommendations  
 12                  from all birth defects research conferences sponsored  
 13                  by the Centers for Disease Control and Prevention,  
 14                  including conferences related to spina bifida; and”;

15                  (4) by redesignating subsections (c), (d), and (e)  
 16                  as subsections (b), (c), and (d), respectively;

17                  (5) by inserting after subsection (d) (as so redes-  
 18                  ignated), the following:

19                  “(e) *ADVISORY COMMITTEE.*—Notwithstanding any  
 20                  other provision of law, the members of the advisory com-  
 21                  mittee appointed by the Director of the National Center for  
 22                  Environmental Health that have expertise in birth defects,  
 23                  developmental disabilities, and disabilities and health shall  
 24                  be transferred to and shall advise the National Center on  
 25                  Birth Defects and Developmental Disabilities effective on



1 *the date of enactment of the Birth Defects and Develop-*  
 2 *mental Disabilities Prevention Act of 2003.”; and*

3 *(6) in subsection (f), by striking “\$30,000,000”*  
 4 *and all that follows and inserting “such sums as may*  
 5 *be necessary for each of fiscal years 2003 through*  
 6 *2007.”.*

7 **SEC. 3. TECHNICAL CORRECTIONS FOR STATE COUNCILS**  
 8 **ON DEVELOPMENTAL DISABILITIES.**

9 *(a) IN GENERAL.—Section 122(a) of the Develop-*  
 10 *mental Disabilities Assistance and Bill of Rights Act of*  
 11 *2000 (42 U.S.C. 15022(a)) is amended—*

12 *(1) in paragraph (3)(A)(ii), by inserting before*  
 13 *the period the following: “, the amount received by the*  
 14 *State for the previous year, or the amount of Federal*  
 15 *appropriations received in fiscal year 2000, 2001, or*  
 16 *2002, whichever is greater”; and*

17 *(2) in paragraph (4)(A)(ii), by inserting before*  
 18 *the period the following: “, the amount received by the*  
 19 *State for the previous year, or the amount of Federal*  
 20 *appropriations received in fiscal year 2000, 2001, or*  
 21 *2002, whichever is greater”.*

22 *(b) EFFECTIVE DATE.—The amendments made by sub-*  
 23 *section (a) shall take effect on October 1, 2003 and apply*  
 24 *to allotments beginning in fiscal year 2004.*

1 **SEC. 4. REPORT ON SURVEILLANCE ACTIVITIES.**

2       *Not later than 18 months after the date of enactment*  
3 *of this Act, the Secretary of Health and Human Services*  
4 *jointly with the Secretary of Education shall submit to the*  
5 *Committee on Health, Education, Labor, and Pensions of*  
6 *the Senate and the Committee on Energy and Commerce*  
7 *and Committee on Education and the Workforce of the*  
8 *House of Representatives a report concerning surveillance*  
9 *activities under section 102 of the Children's Health Act*  
10 *of 2000 (Public Law 106–310), specifically including—*

11           *(1) a description of the current grantees under*  
12 *the National Autism and Pervasive Developmental*  
13 *Disabilities Surveillance Program and the Centers of*  
14 *Excellence in Autism and Pervasive Developmental*  
15 *Disabilities the data collected, analyzed, and reported*  
16 *under such grants, the sources of such data, and*  
17 *whether such data was obtained with parental consent*  
18 *as required under the Family Educational Rights*  
19 *and Privacy Act of 1974 (20 U.S.C. 1232g);*

20           *(2) a description of current sources of data for*  
21 *the surveillance of autism and developmental disabil-*  
22 *ities and the methods for obtaining such data, includ-*  
23 *ing whether such data was obtained with parental or*  
24 *patient consent for disclosure;*

25           *(3) an analysis of research on autism and devel-*  
26 *opmental disabilities with respect to the methods of*

1       *collection and reporting, including whether such re-*  
2       *search was obtained with parental or patient consent*  
3       *for disclosure;*

4               (4) *an analysis of the need to add education*  
5       *records in the surveillance of autism and other devel-*  
6       *opmental disabilities, including the methodological*  
7       *and medical necessity for such records and the rights*  
8       *of parents and patients in the use of education*  
9       *records (in accordance with the Family Educational*  
10       *Rights and Privacy Act of 1974);*

11              (5) *a description of the efforts taken by the Cen-*  
12       *ters for Disease Control and Prevention to utilize edu-*  
13       *cation records in conducting the surveillance program*  
14       *while obtaining parental or patient consent for such*  
15       *education records, including the outcomes of such ef-*  
16       *forts;*

17              (6) *a description of the challenges provided to ob-*  
18       *taining education records (in the absence of parental*  
19       *or patient consent) for the purpose of obtaining addi-*  
20       *tional surveillance data for autism and other develop-*  
21       *mental disabilities; and*

22              (7) *a description of the manner in which such*  
23       *challenges can be overcome, including efforts to edu-*  
24       *cate parents, increase confidence in the privacy of the*  
25       *surveillance program, and increase the rate of paren-*

1        *tal or patient consent, and including specific quan-*  
2        *titative and qualitative justifications for any rec-*  
3        *ommendations for changes to existing statutory au-*  
4        *thority, including the Family Educational Rights*  
5        *and Privacy Act of 1974.*



**Calendar No. 369**

108TH CONGRESS  
1ST SESSION

**S. 286**

**[Report No. 108-188]**

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**A BILL**

To revise and extend the Birth Defects Prevention  
Act of 1998.

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NOVEMBER 6, 2003

Reported with an amendment